

My name is Melanie and I am a CF mom. I am writing this because I passionately believe that this panel should approve infant CF screenings. My 12 year old daughter Tiffani was diagnosed with CF two years ago after suffering from a decade of ear infections, sinus infections, chronic strep throat, reflux and countless pneumonia's.

On September 24<sup>th</sup> 1995 we were blessed with the arrival of our beautiful daughter. Anxious to meet us, Tiffani came screaming into this world two months premature and weighed a meager 3 pounds. Her first month was spent in the NICU mastering how to eat and gaining precious ounces. The year that followed was a roller coaster ride, we brought her home briefly, only to return to the hospital every five weeks or so for an extended stay, convinced her health concerns were a result of her prematurity.

Once Tiff started school she seemed to be a magnet to any and every virus and bacteria that came her way. We spent many a sleepless night battling raging fevers which were always accompanied by violent vomiting. In my gut I knew it was not normal. Holding her hair away from her face I prayed that the thick sticky mucus that would continuously get stuck in her airway would release itself so she could breathe again. Always brave, she eventually got it out- which was and is no easy feat.

Doctors predicted Tiffani would catch up growth wise with her peers by the time she reached second grade or so. Instead we saw an increasing discrepancy between her height and her classmates, even though she was a good year older than most in her grade. We attributed her lack of growth to her recurrent infections. The end of Tiffani's second grade year was clouded by a debilitating pneumonia that took her several months to recover from. Her frail body got cold quickly in the dead of summer and her energy was depleted. The year and a half that followed was met with five more bouts of pneumonia, a frustrating and scary time for our family.

Ten years after her arrival in this world doctors were able to conclusively tell us Tiffani has cystic fibrosis. As much as this is not a diagnosis a parent wants to hear- we found relief in it. We had answers. Knowledge is power. Tiffani started treatments immediately. Now when she gets sick I am not afraid she is going to choke on the thick sticky mucus and the fevers are no longer as violent. She is receiving the correct treatment and now her health is manageable.

Once we were educated about Tiffani's CF diagnosis we were able to address her growth issues. Four months after learning of her CF we found out Tiffani also has Turner's syndrome, a defect on an X chromosome, which inhibits her growth. Her type of Turner's is one that carries the most complications. Tiffani has only one horseshoe shaped kidney, an under active thyroid, hearing loss, and other concerns that will need continuous monitoring. Immediately she started treatment for Turner's which includes, growth hormone, and thyroid medication along with regular monitoring from an endocrinologist.

As I write this I realize you are probably asking yourself "Didn't this woman ever take her child to the doctor...how could they not know about these serious medical conditions until she was ten?" The fact is I was constantly at the pediatrician's office and the asthma care team's office with Tiffani. Almost always her health issues were attributed to her pre-maturity, which made sense. HOWEVER, had there been an infant screening for CF we would have had answers immediately. She would have avoided painful bouts with pneumonia. Her growth problems would have been addressed sooner and her growth potential outcome would've been much better than it is now because treatment would've started sooner. Since Tiffani has started treatment she has become a new child- healthy, confident, and positive about her future. The sooner a child with CF can receive treatment the brighter their future will be. *Everyone deserves a bright future.*

Please approve this bill to require infant screenings for cystic fibrosis.

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